

# Iowa Prevention of Disabilities Policy Council

Annual Report for November 1, 2013 – October 31, 2014

100 Hawkins Drive  
277 Center for Disabilities and  
Development  
Iowa City, Iowa 52242

October 31, 2014

The Honorable Governor Terry E. Branstad  
Members of the General Assembly

## **Executive Committee**

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Cheryll Jones, Ottumwa

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## **Administrator**

Kay DeGarmo  
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Dear Governor Branstad and Members of the General Assembly:

The Prevention of Disabilities Policy Council respectfully submits its annual report to the Governor and General Assembly pursuant to the requirements of Iowa Code 225B.3.

The Council remains committed to working with the Governor, General Assembly, state departments and private sector to optimize state efforts to prevent disabilities from occurring and minimize the effects of disabilities that have occurred for all Iowa citizens.

This report discusses the Council's December 2013 Disability Policy Summit, describes the process used to prioritize the Summit's 27 recommendations and presents the top 5 recommendations for action. The report also highlights the Council's major activities and accomplishments over the past year.

The Council's 2015 agenda, which includes specific recommendations for consideration by the Governor and the General Assembly, is being finalized and will be made available in early December 2014.

The Council thanks you for the opportunity to provide you with this information and stands available to answer questions and receive comments.

Sincerely,

Cheryll Jones, Chair, Ottumwa, Iowa  
641-682-8145

## Disability in Iowa

People with disabilities are Iowa's largest minority population. Over 10% of non-institutionalized Iowans of all ages have a disability that affects their ability to learn, work, communicate, perform activities of daily living, or participate in everyday community life. These disabilities are the result of genetics, environmental factors, injury, or illness. They may occur at any point in life and may be mild, severe, or intermittent. Those who have a disability are often at risk of developing a secondary condition that can further reduce their independence.

Iowans with disabilities can experience significant social disparities. They are much more likely than their non-disabled peers to be unemployed; they can have significantly less household income; and they often have considerably higher poverty rates. Disabilities may cause very costly problems for the individuals affected, their families, and government in terms of both quality of life and financial expenditure.

Most disabilities are due to conditions that can be prevented using known evidenced-based practices. Effective prevention practices include actions that prevent a disability from occurring (*Primary prevention*), approaches that support early identification and intervention (*Secondary prevention*), and strategies that reduce the effects of a disability (*Tertiary prevention*). Addressing this crucial prevention effort is the primary role of the Prevention of Disabilities Policy Council.

## Role of the Council

The Iowa Prevention of Disabilities Policy Council is responsible for facilitating policy development and coordinating multiple state agency and public-private activities to prevent disability and to improve the health and independence of those with disabilities. It is charged with advising the Governor and the Iowa General Assembly about priorities and policies in preventing disability and secondary conditions. The Council's core mission is to improve lives, increase independence, and save money through prevention. It is the only Iowa Council with this primary role.

Unlike most governmental entities, the Council does not directly operate programs; instead it works across the state departments and the private sector to carry out its mission. The Council annually reviews the environment and selects priority areas on which to focus its work. The Council's priority areas in 2014 included:

- Preventing injuries that result in disability
- Optimizing child health and development
- Building inclusive, accessible communities that foster independence and access to needed care and support

Each of these priorities falls under the larger goal of improving access to health care for Iowans with disabilities.

## Accomplishments

### **2013 Disability Policy Summit: Preventing Disabilities and Ensuring Access to Care**

In 2013, the Iowa General Assembly authorized and funded the Iowa Prevention of Disabilities Policy Council (Council) to conduct a summit to develop a state agenda and provide policy recommendations regarding the prevention of disabilities and their secondary conditions. The daylong **2013 Disability Policy Summit: Preventing Disabilities & Ensuring Access to Care** took place on December 5, 2013 in Ankeny, Iowa.

In choosing the topics to be covered during the Summit, the Council determined that the topics chosen should address prevention across the life span and at all three levels, i.e., *primary*, *secondary* and *tertiary* prevention. The Council gave preference to topics for which there were significant unmet needs and for which an investment in prevention would yield substantial results. After consulting with the Summit's 15 co-sponsors and other disability partners, the Council selected the following three topics to be addressed at the Summit:

- Preventing injuries that result in disability
- Supporting children and families to optimize child health and development
- Building inclusive, accessible communities that foster independence and access to healthcare

The Summit drew approximately 130 participants who developed 27 recommendations for state policy makers to consider. The recommendations affect both state and program policy. As required by the authorizing legislation, a final report of the Summit was filed with the General Assembly on February 5, 2014. A copy of the Summit final report can be found at [http://www.pdpciowa.org/wp-content/uploads/SummitReport/Iowa\\_PDPC\\_Disability\\_Policy\\_Summit\\_Report\\_2\\_5\\_14.pdf](http://www.pdpciowa.org/wp-content/uploads/SummitReport/Iowa_PDPC_Disability_Policy_Summit_Report_2_5_14.pdf).

### **Prioritizing the Summit recommendations**

The Council conducted an analysis of the Summit's 27 recommendations, determining which would require legislative action, which could be addressed by administrative rule, which could be addressed by executive branch action, and which would need further study before action could be initiated. The Council then convened representatives of 13 state boards, commissions and programs serving people with disabilities for a "Meeting of the Minds" event in July 2014 to review the Council's policy analysis and prioritize the recommendations. Under the guidance of a facilitator, the group selected the top recommendation(s) from each of the Summit topics based upon measures of importance, impact, and feasibility. They ranked the recommendations and developed a report for each ranked recommendation that defined (a) partners that could be gathered in support of the issue, (b) the measure of "victory," and (c) the challenges the Council might face in promoting the recommendation.

The Council reviewed the final Summit report and the report from the “Meeting of the Minds” event during its regular August 2014 meeting and selected 5 recommendations to move forward in the coming year. (These recommendations are summarized on the final page of this report.)

## Activities and Actions

The Council conducted the following activities and took the following actions on its priority areas this year.

### **Preventing injuries that result in disability**

Injury remains the leading cause of disability for those individuals between the ages of 4 and 44. It is also an important cause of disability among seniors and a significant cause of secondary disability among individuals that have an existing disability. New research that demonstrates the link between sports-related concussion and disability provides the opportunity to institute improved concussion prevention measures in organized sports, especially in organized sports involving Iowa’s school-age children.

Falls are currently the leading cause of brain injury. They also contribute to a decreased ability to perform household tasks, a reduced quality of life, and possible loss of independence. Recent Iowa data show that injuries and deaths from falls have increased 20% over the last decade. Older adults and individuals with disabilities are at increased risk for falls. Among these two groups, most falls occur in the home.

This year, the Council . . .

- Collaborated in the Brain Injury Alliance of Iowa’s effort with the 85<sup>th</sup> Iowa General Assembly to extend Iowa’s Sports Concussion law to cover youth of all ages in all organized sports venues.
- Met with the Director of the Iowa Department of Public Health, to discuss the Summit recommendation to provide funding for an injury prevention program within the department.
- Began working with the Iowa Department of Public Health Office of Disability, Violence and Injury Prevention to determine the feasibility of assessing injuries among individuals with disabilities as part of a new injury study.

### **Optimizing child health and development**

Disabilities that occur during pregnancy or childhood, particularly in early childhood, are the leading cause of lifelong disability. Scientific evidence about early brain development has highlighted the importance of addressing childhood development in the early years in order to

avoid disability. Adverse Childhood Experiences (ACEs) are stressful or traumatic experiences, including abuse and a range of family dysfunction issues. Studies conducted in the past 15 years show that ACEs are strongly related to the adoption of risky health behaviors; the development of disease, disability, and social problems; and early death in adulthood. There is also a strong relationship between ACEs and adult mental health problems.

This year, the Council . . .

- Recommended to the Governor and the 85<sup>th</sup> Iowa General Assembly the continued development and expansion of programs, practices, and systems that improve healthy development and children's behavioral health while building upon the work of 1<sup>st</sup> Five and ACEs.
- Continued working with the Iowa Medicaid Enterprise to monitor Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program outcomes, identify opportunities for effective preventive activities, and further develop the Assuring Better Child Health and Development (ABCD) recommendations to Medicaid.
- Reviewed the Summit recommendation to create a children's disability services system and reviewed the work of the Systems Redesign Children's Workgroup to determine the status of prevention and early identification priorities in system planning.

### **Building inclusive, accessible communities that foster independence and access to needed care**

The Council believes that people with conditions such as cerebral palsy, limb loss, visual impairments, and heart disease need not become disabled or will only experience mild disability if they have full access to community environments, activities, and services. Although the Americans with Disabilities Act (ADA) has brought about many improvements in access, there is more to do. Iowa has some of the oldest housing in the country and a shortage of housing that is accessible for people with disabilities. Overwhelmingly, individuals with disabilities want to live in a home environment, those who acquire a disability want to be able to remain in their own homes, and seniors want to be able to "age in place." Additionally, to achieve this goal, it is important that Iowa's redesigned system of services for adults with disabilities is adequately funded so that individuals do not have to wait for several years to access needed services, and so that programs are in place to support the state's preference for community-based services. Providing adequate and timely services that meet individual needs will prevent the use of more costly services down the road and will improve the quality of life for Iowans who have disabilities.

The Council . . .

- Considered the feasibility of creating an Iowa income tax credit for costs incurred in retrofitting a primary residence to accommodate a disability and developed specific recommendations for how the tax credit would work.
- Supported an Olmstead 2014 legislative recommendation to create a Legislative Study

Committee to review Iowa's HCBS Waiver system and develop recommendations to improve equity, enhance flexibility, prevent institutionalization, support transitioning from institutional settings, and build community capacity.

- Discussed with the Iowa Department of Human Services, Iowa Medicaid Enterprise, and other partnering state disability programs the need for changes to improve equity, enhance flexibility, prevent institutionalization, and build community capacity through Iowa's Home and Community-Based Services Waiver program.

## **Improving access to health care for people with disabilities**

In addition to holding the Policy Summit and "Meeting of the Minds" event, the Council continued its ongoing activities in reviewing prevention policy issues related to improving access to health care for people with disabilities. Children and adults with disabilities are often at risk of developing secondary health conditions that can add to their level of disability and increase their level of dependence on specialized services and supports. People with disabilities frequently face numerous barriers in accessing health care services including cost, transportation, accessibility of health care environments and equipment, availability of services, inconsistent health care provider communication skills and training, and limited provider time with patients during visits because of current reimbursement methodologies. The Council believes that assuring access to needed health care for people with disabilities will prevent many complications and secondary conditions that are costly for the individual and the state.

This year the Council . . .

- Examined the need for and benefits of telehealth services for individuals with disabilities and learned about current user issues with coverage of telehealth services in Iowa.
- Met with representatives of the Iowa Medicaid Enterprise and Wellmark Blue Cross and Blue Shield to share the Summit recommendation on telehealth coverage and discuss each organization's policy on telehealth coverage and reimbursement.
- Agreed to continue discussions with the Iowa Medicaid Enterprise, Wellmark Blue Cross and Blue Shield, and other private insurers about policy changes to improve access to telehealth services for Iowans with disabilities.
- Provided support for the Iowa Department for the Blind's application for a grant from the Alma Pedretti Charitable Foundation that would support health coaching and education for their clients living in Boone, Dallas, Jasper, Story, and Polk Counties.
- Provided advice and assistance to the Iowa Department of Public Health "Improving the Health of Iowans with Disabilities" grant from the Centers for Disease Control and Prevention. Specifically, the Council:
  - reviewed and provided recommendations regarding the content and dissemination of the Iowa Department of Public Health public health needs assessment for Iowans with disabilities
  - reviewed responses to the 2011 Iowa Behavioral Risk Factor Surveillance System

(BRFSS), which included additional state survey questions about the need of people with disabilities for assistance with evacuation in emergencies, expected use of community shelters, and other needs for assistance during emergencies. The Council provided recommendations about dissemination of the data to agencies to be used in state and local emergency preparedness planning

- reviewed and provided recommendations for the piloting and dissemination of a new video to train health care providers in effective communication and accommodation for patients with disabilities
- recommended questions to be added to the 2015 Iowa BRFSS survey to gather information about the adequacy of health care coverage for Iowans with disabilities since the implementation of the Iowa Health and Wellness Plan in 2013

## Recommendations

The Council has approved the following recommendations to the Governor and the 86<sup>th</sup> Iowa General Assembly:

- Create a state income tax credit for the costs incurred in retrofitting a primary residence to accommodate a disability.
- Assure consistent public and private insurance coverage for telehealth services that meet the needs of Iowans with disabilities.
- Appoint a Governor's task force composed of state officials and key stakeholder groups to identify changes that can be made immediately to Iowa's HCBS System Waivers to improve equity, enhance flexibility, prevent institutionalization, and build community capacity.
- Instruct the Department of Human Services to prioritize development of a children's disability services system that includes prevention and early intervention and provide sufficient funding to the department to carry out this charge.
- Provide funding to strengthen Iowa's infrastructure for injury prevention and related research.

A document that provides additional information about the Council's recommendations to the Governor and 86<sup>th</sup> Iowa General Assembly will be made available in December 2014.